ORIGINAL ARTICLE

"Dear hair loss"—illness perceptions of female patients with chemotherapy-induced alopecia

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Abstract

Objective Chemotherapy-induced alopecia (CIA) is one of the most common and distressing side effects of chemotherapy treatment. This study aims to assess the illness perceptions of female patients dealing with CIA, and their associations with demographic and clinical characteristics, coping strategies, and quality of life. The secondary aim was to compare the illness perceptions of patients with CIA with other samples, to help elucidate the specific perceptions of patients with CIA.
Method Forty female patients at risk of severe hair loss due to chemotherapy treatment were included at the oncological daycare unit of a teaching hospital in the Netherlands. Patients were asked to complete the Brief-Illness Perception Questionnaire (B-IPQ) and the Hair Quality of Life (Hair-QoL) questionnaire.
Results Illness perceptions indicated that although patients understood their hair loss, they lacked being able to make sense of managing it, negatively impacting patients' lives. Psychological quality of life was significantly correlated with the B-IPQ domains: consequences, degree of concern, and emotional response. Social quality of life was significantly correlated with psychological quality of life. Patients with CIA felt significantly less able to manage their hair loss, compared to patients with breast cancer and psoriatic arthritis.
Conclusion As patients' beliefs of being able to manage their hair loss are important for adopting and maintaining adequate coping behaviors, additional effort of health care providers in fostering patients' sense of control is indicated, focusing on patients' strengths during and after chemotherapy treatment. In the context of developing interventions for patients with CIA, consequences, concern, and emotional response are the major dimensions that should be taken in account to help patients deal with hair loss.

Keywords Illness perceptions · Chemotherapy-induced alopecia · Common Sense Model · Psychological impact · Coping · Quality of life

Introduction

Hair is considered a major indicator of beauty, age and femininity/masculinity, and plays a major role in one's appearance [1]. Not only scalp hair, also eyebrows and eyelashes are essential for facial expressions and identity, as hair is a way of expressing oneself [2]. The severity of hair loss can range from partial to complete hair loss and can occur suddenly or more gradually over time [3]. The sudden, severe loss of hair is generally a visual indicator of illness [4, 5], which invades privacy and becomes a public matter [6, 7]. Therefore, the loss of hair is associated with a high impact, leading to changes in body image, lowered self-esteem [8], loss of identity [2, 7], problems in social life [1], increased anxiety, and a lowered health-related quality of life [2, 5].

Chemotherapy-induced alopecia (CIA) is one of the most common side effects of cancer treatment. Patients rate CIA as one of the most traumatizing side effects [1, 6, 7, 9]; for some patients, CIA is even the reason to decline treatment [10]. As the impact of alopecia is not directly related to the degree of hair loss [5, 6], this impact might be partially determined by patients' cognitive and emotional perceptions.

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The Common Sense Model outlines that illness perceptions influence patients' coping strategies, indirectly affecting health outcomes [11, 12]. This relationship has been shown in the literature for a wide range of conditions [13]. A recent development in this field is the use of self-regulatory interventions, encouraging patients to reflect on and change their illness perceptions and coping strategies in order to affect treatment outcomes. An example is the controlled trial of Richardson et al. [14], targeting illness perceptions in patients with newly diagnosed head and neck cancer, contributing to more adaptive and constructive illness perceptions of treatment and social functioning.

Although the impact of CIA is very high for patients, healthcare providers with a medical background tend to underestimate its impact [6, 15]. The study of Paterson et al. [16] shows that patients experience unmet supportive care needs related to hair loss, pertaining to the preparedness and information about potential coping strategies [4], information provision about the option to use scalp cooling, and information about the working mechanisms of scalp cooling [17]. This is illustrated by the observation that women believe that scalp cooling would prevent the loss of eyebrows/eyelashes [18, 19]. Scalp cooling is the only proven effective method to reduce the loss of hair [20–22]. However, scalp cooling is not applicable for hematological cancers and the impact of hair loss is even higher and more distressing when scalp cooling has insufficient results [23]. Another frequently used patient initiated strategy is the use of head covering, where patients try to regain control over their appearance [1].

A previous study by our group presented the pictorial representation of hair loss in patients with CIA. The associated illness perceptions, as reflected in their scores on the Brief-Illness Perception Questionnaire (B-IPQ) corroborated the characteristics of the drawings. For instance one patient wrote, "I always wear a cap or wig when I'm at home. Looking in the mirror is confronting." In addition, in our study all patients confronted with CIA emphasized its emotional impact (e.g. shame, insecurity, sadness) [24].

Interventions in oncology care for patients with CIA mainly focus on the prevention of the dreaded phenomenon [21, 25]. Relatively few interventions have been developed and implemented to help patients prepare for, and actually cope with CIA and its consequences. Examples of such interventions are an aesthetic care/wig program [26], online peer support groups [27], and Help with Adjustment to Alopecia by Image Recovery (HAAIR: a computer-imaging program that simulates baldness and wig use by the patient) [28]. However, none of these interventions are used in regular care as there is limited evidence for their efficacy, and the impact of chemotherapy-induced alopecia is underestimated by healthcare providers [29].

Our current study assesses illness perceptions of female patients with CIA and their associations with demographic and clinical characteristics, coping strategies, and quality of life. The secondary aim was to compare the illness perceptions of patients with CIA with other reference samples, shedding light on the specific illness perceptions in patients with CIA. Our study contributes to establishing further work in attempts to address illness perceptions and make them more adaptive and constructive, in line with related research in the theoretical context of the Common Sense Model [11, 30].

Methods

Sample and settings

Forty female patients were recruited from the oncological daycare unit at Máxima Medical Centre Eindhoven/Veldhoven in the Netherlands (Ethics Committee number N17.148). Inclusion criteria were (1) female patients ≥ 18 years old, (2) who had at least two cycles of chemotherapy treatment by intravenous infusion with a chance of severe hair loss, and (3) their last treatment was a maximum of one month ago. These criteria were determined based on the findings that hair loss, as well as possible results of scalp cooling, becomes visible after two cycles of chemotherapy [31]. Severe hair loss was defined as patients' eligibility for scalp cooling and/or the possibility to receive a wig reimbursement prescription from the health care insurance, which was determined by the patient' physician. Patients who were bald before the start of this study and patients with insufficient proficiency in Dutch to fill out the questionnaires were excluded.

Patients who matched the criteria were informed about the study and asked to participate by a nurse at the oncological daycare unit during their chemotherapy treatment. Informed consent was obtained from all patients.

Measures

Demographic and clinical characteristics were obtained by a questionnaire for: age, marital status, ethnic background, educational level, family situation, work, and social activities. Clinical characteristics included the cancer diagnosis, whether a patient had undergone surgery for cancer, previous hair loss due to cancer treatment, whether the patient had received information about scalp cooling and used scalp cooling during treatment, loss of eyebrows and eyelashes, the usage of head covering, and satisfaction of the information provision about the cancer treatment and the possible hair loss.

The validated Dutch version of the *Brief-Illness Perception Questionnaire (B-IPQ)* [32] was used to assess the emotional and cognitive perceptions of chemotherapy-induced alopecia. As the designers of the B-IPQ questionnaire encourage researchers to adapt the phrasing of the instructions for filling out the B-IPQ to the sample of respondents in their study [32], the word "illness" was replaced by "hair loss" in all items. The open-ended question about causal attributions was modified from "causes" to "effects" of hair loss. This resulted in phrasing the item assessing "causal attributions" as "The three most important effects of hair loss to me are …". Illness perceptions were measured with the B-IPQ on eight dimensions: consequences, timeline (patients' expected duration of their hair loss), personal control, treatment control, identity, concern, coherence, and emotional representation (Table 3). As outlined in our earlier study, answers to the open-ended question of the B-IPQ were categorized into five themes: type of effect, impact, coping/process, feelings about one's appearance, and interaction in social life [33]. Patients' scores on the B-IPQ of the current sample were compared with reference samples of patients with CIA ($N = 15$) [24], alopecia areata ($N = 243$) [34], breast cancer ($N = 22$) [35], and psoriatic arthritis ($N = 83$) [36].

Coping was operationalized by two items, i.e., (1) the use of head covering (yes–no) and (2) the use of scalp cooling during chemotherapy treatment (yes–no). Coping was categorized into three categories and scored as follows: when both strategies were used (2), when one of the two was used (1), and when none of the strategies was used (0).

The *Hair Quality of Life (Hair-QoL)* questionnaire comprises 43 questions that aim to assess the meaning and impact of hair loss, the self-rated amount of hair loss using a VAS-scale (0–100%), the impact of hair loss on social life, the use of head covering, and regrowth of hair. This English questionnaire (C. van den Hurk, personal communication, September 4, 2017) was translated into Dutch by three independent researchers. From the 43 items, items were selected that assess psychological, social, and functional quality of life for patients with CIA specifically. This resulted in 13 items that reflected the psychological, six items for social, and two items for functional quality of life associated with the loss of hair; 21 items in total, therefore. The internal consistency of psychological quality of life was high ($N = 13$, $\alpha = 0.851$), as well as for social quality of life ($N = 6$, $\alpha = 0.790$). The internal consistency for the two items of the functional quality of life was low, as one item concerned patients' work status: "How much does the appearance of your hair impact on continuing your normal work?" Almost half of the patients were unemployed in this study, leading to many missing values on this item. Therefore, the functional quality of life is reflected in one item: "In relation to your hair loss, have you felt able to carry on with your life as normal despite your hair loss?" Items were answered on a 4-point Likert scale.

Statistical analysis

The descriptive analysis was performed using IBM SPSS Statistics for Windows, version 26 (IBM Corp., Armonk, N.Y., USA). The answers on the open-ended question regarding the perceived effects of chemotherapy-induced alopecia of the B-IPQ were categorized into themes by one researcher. Means and standard deviations of the B-IPQ were calculated and scores were compared to reference groups based on the literature [13]. Differences between the B-IPQ in the current sample and comparison groups of patients with CIA [24], alopecia areata [34], breast cancer [35], and psoriatic arthritis [36] were tested using *t*-tests. Level of significance for this analysis was set at $P \leq 0.01$ because of multiple comparisons. Scales were formed for coping strategies and the psychological and social quality of life. Mean scores were calculated and the associations between constructs of the Common Sense Model were calculated using bivariate correlations between the illness perceptions and (1) demographic and clinical characteristics; (2) coping strategies; (3) psychological, social, and functional quality of life.

Results

Demographic and clinical characteristics

The demographic and clinical characteristics of the patient sample are summarized in Table 1. Forty female patients between age 31 and 83 ($M = 57$, $SD = 13.6$ years) participated in this study. Most patients were Caucasian (90%) and 27 patients were diagnosed with breast cancer (68%). The degree of hair loss on the VAS scale varied from 0 to 100, with a mean score of 59 ($SD = 37.4$). Four patients did not experience any hair loss yet (10%), whereas 14 patients experienced the complete loss of hair (35%). Seven patients (17%) had previous hair loss due to chemotherapy treatment.

Illness perceptions: B-IPQ

The highest scores on the B-IPQ were reported on coherence and consequences, indicating patients understood their hair loss ($M = 7.63$, $SD = 2.85$) and hair loss affected patients' life considerably ($M = 6.18$, $SD = 3.46$). The lowest scores were on identity and personal control, showing that patients attributed relatively few symptoms to hair loss ($M = 1.83$, $SD = 2.14$) and that patients perceived lacking control over the hair loss ($M = 2.10$, $SD = 2.74$). The B-IPQ scores are presented in Table 2.

Table 1 Demographic and clinical characteristics ($N = 40$)

Characteristics	N (%)
Age	
Mean (*SD*) (year)	57 (13.6)
Marital status	
Married	27 (68%)
Living with partner	5 (13%)
Widow	5 (12%)
Divorced	2 (5%)
Unknown	1 (2%)
Ethnicity	
Caucasian	36 (90%)
East European, Chinese	2 (5%)
South European, Indian	1 (3%)
Mixed or else	1 (2%)
Cancer type	
Breast cancer	27 (68%)
Bowel cancer	1 (2%)
Lung cancer	5 (13%)
Kidney cancer	1 (2%)
Other	6 (15%)
Previous alopecia due to cancer treatment	
Yes	7 (17%)
No	33 (83%)
Hair loss eyelashes	
No hair loss eyelashes	21 (53%)
Partial hair loss eyelashes	13 (32%)
Complete hair loss eyelashes	6 (15%)
Hair loss eyebrows	
No hair loss eyebrows	21 (52%)
Partial hair loss eyebrows	10 (25%)
Complete hair loss eyebrows	9 (23%)
Patient reported degree of hair loss	
(score 0–100)	59.16 (37.43)
Mean (*SD*)	
Scalp cooling during chemotherapy	
Yes	22 (55%)
No	18 (45%)
Head covering	
Wig	13 (33%)
Another type of head covering	3 (7%)
Both wig and other	4 (10%)
No head covering yet	20 (50%)

The answers to the open-ended question regarding the three most important effects of patients' baldness were categorized into five themes: type of effect ($n = 13$), impact ($n = 11$), coping/process ($n = 9$), feelings about appearance ($n = 10$), and interactions in social life ($n = 11$) (Table 3). Most patients mentioned the loss of one's personal identity/transitioning into a cancer patient ($n = 10$), a changed appearance ($n = 6$), changes in one's mood/feeling upset ($n = 5$), and the loss of self-confidence ($n = 4$). Nine patients did not describe any effects of their alopecia, of whom two patients did not experience any hair loss (yet).

Comparing the illness perceptions of patients with chemotherapy-induced alopecia with reference groups

Compared to an earlier study of our group also including the B-IPQ for female patients with CIA [24], patients in the current study attributed more symptoms to the hair loss ($P = 0.006$). In addition, for three dimensions trends in differences were found, indicating more negative consequences ($P = 0.012$), expecting a more chronic timeline ($P = 0.016$), and higher concerns ($P = 0.011$) in the current study.

Compared to patients with alopecia areata [34], a chronic dermatological condition characterized by the sudden loss of hair, patients in our sample with CIA experienced a less chronic timeline ($P < 0.001$) and attributed fewer symptoms to the experienced hair loss ($P < 0.001$). Compared to Dutch patients with breast cancer [35], patients with CIA experienced less personal control ($P < 0.001$), less treatment control ($P < 0.001$), and attributed fewer symptoms to their hair loss ($P < 0.001$).

Compared to patients with psoriatic arthritis [36], a condition also with potentially major visible consequences, patients with chemotherapy-induced alopecia experienced a less chronic timeline ($P < 0.001$), less personal control ($P < 0.001$), less treatment control ($P < 0.001$), and attributed fewer symptoms to their hair loss ($P < 0.001$). The B-IPQ scores and comparisons are presented in Table 2.

Coping

Frequently used coping strategies for patients with CIA are the use of scalp cooling and head covering. As scalp cooling is not compatible for all types of cancer, 32 patients reported to be informed about scalp cooling (80%), of whom 22 patients actually received scalp cooling (55%).

The use of head covering was reported by 50% of the patients, with wigs being reported most frequently, by 13 patients (33%). Four patients used a wig, as well as another type of head covering (10%) and three patients used another type of head covering, e.g., scarf or cap (7%). Of the patients using a head covering, 64% described an improvement in feelings.

Eight patients did not use either one of the coping strategies: head covering or scalp cooling (20%). Twenty-three patients used one of the two coping strategies (57.5%), whereas nine patients used scalp cooling, as well as head covering (22.5%). An overview of these coping strategies is presented in Table 4.

Quality of life

Quality of life comprises three aspects: psychological, social, and functional quality of life. Scores range from

Table 2 Comparison of B-IPQ scores between patients with chemotherapy-induced alopecia and reference groups (mean ± SD)

B-IPQ	Chemotherapy- induced alopecia (N = 40) Current study	Chemotherapy-induced alopecia (N = 15) Van Alphen et al. (2020)	Alopecia areata (N = 243) Willemse et al. (2019)	Breast cancer (N = 22) Kaptein et al. (2013)	Psoriatic arthritis (N = 83) Kotsis et al. (2012)
Consequences	6.18 ± 3.46	3.47 ± 3.36	5.93 ± 2.87	7.36 ± 1.87	5.47 ± 0.42
Timeline	3.93 ± 2.44	2.20 ± 1.86	9.14 ± 1.83**	5.45 ± 2.79	8.81 ± 0.35**
Personal control	2.10 ± 2.74	2.27 ± 3.59	2.01 ± 3.61	4.90 ± 2.95**	6.95 ± 0.42**
Treatment control	2.70 ± 3.53	-	1.69 ± 2.62	8.32 ± 1.89**	8.11 ± 0.33**
Identity	1.83 ± 2.14	0.53 ± 1.13*	5.12 ± 3.38**	4.27 ± 2.57**	5.13 ± 0.39**
Concern	4.83 ± 3.84	1.93 ± 2.91	5.84 ± 3.50	6.50 ± 2.70	5.99 ± 0.49
Coherence	7.63 ± 2.85	6.40 ± 4.05	6.78 ± 3.13	6.80 ± 2.73	7.13 ± 0.33
Emotional response	4.86 ± 3.58	3.73 ± 3.49	5.90 ± 3.38	5.77 ± 2.98	5.70 ± 0.49

*$P < 0.01$, **$P < 0.001$ compared to the current study

1 to 4, with higher scores indicating a higher quality of life. Psychological quality of life, consisting of 13 items, has a mean score of 2.54 ($SD = 0.67$). Social quality of life consisted of six items and has a mean score of 2.90 ($SD = 0.72$). Most patients were less worried about the loss of hair in relation to close relatives and family compared to interaction with strangers. The functional quality of life consisted of one item, with a mean score of 3.20 ($SD = 0.81$). An overview of the scores on quality of life is presented in Table 5.

Associations between constructs of the Common Sense Model: illness perceptions and their relations with sociodemographic and clinical characteristics

No significant associations were found between demographic and clinical characteristics and illness perceptions. This important finding is consistent with related research on how patients with a chronic somatic illness make sense of their condition [37]. Similarly, coping and quality of life were unrelated to sociodemographic and clinical characteristics (all P-values > 0.05). No significant differences were found between the coping styles and the B-IPQ domains ($P > 0.05$).

Table 3 Answers to the open-ended question of the B-IPQ

Theme	Patient reported effects of alopecia (B-IPQ) Answer (no. of patients)
Type of effect	Being a cancer patient / loss of identity (10) Older appearance (2) Loss of femininity
Impact	Mood changes/upset (5) Loss of self-confidence/feeling insecure (4) Confronting Self-confident
Coping/process	Head covering (2) Developing acceptance (2) Missing my own hair Another side-effect, already suffered so much Fear that my hair will regrow very thin Felt bad when it started (hair loss) Trust that my hair will regrow
Feelings about appearance	Changed appearance (6) Loss of beauty (2) Prettier hair than my natural hair Bald face without eyelashes
Interaction in social life	Rather staying home (4) Visibly (ill) for everyone (4) Burdensome for the social setting Don't want to attract attention Questions from my social group

Table 4 Coping strategies

Applied coping strategy	N (%)
Scalp cooling + head covering	9 (22.5%)
One of the two strategies	23 (57.5%)
None of the strategies	8 (20%)

Table 5 Quality of life

Quality of life domain	Mean ± SD
Psychological quality of life	2.54 ± 0.67
Social quality of life	2.90 ± 0.72
Functional quality of life	3.20 ± 0.81

N of items. Psychological quality of life (N = 13), social quality of life (N = 6), and functional quality of life (N = 1)

Associations between illness perceptions

Significant intercorrelations were found between various illness perception domains of the B-IPQ. Treatment control was significantly correlated with personal control ($r = 0.46$, $P = 0.003$). Consequences was correlated with identity ($r = 0.45$, $P = 0.003$), concern ($r = 0.77$, $P < 0.001$), and emotional response ($r = 0.85$, $P < 0.001$). Concern was correlated with identity ($r = 0.43$, $P = 0.006$) and emotional response ($r = 0.73$, $P < 0.001$). In addition, emotional response was correlated with identity ($r = 0.46$, $P = 0.004$).

Furthermore, significant negative correlations were found between the psychological quality of life and consequences ($r = -0.62$, $P < 0.001$), which implies an interaction between psychological quality of life and the perceived consequences of CIA. Psychological quality of life is also negatively correlated to the amount of concern ($r = -0.68$, $P < 0.001$) and emotional response ($r = -0.64$, $P < 0.001$). Social quality of life was correlated with psychological quality of life ($r = 0.36$, $p = 0.03$).

Discussion

In this study, our major research questions have been answered. First, we showed that the concept of CIA is clinically relevant as this study revealed that CIA negatively affected patients' lives considerably on various domains. The experienced effects are substantial; patients reported the loss of their personal identity, a changed appearance, the loss of self-confidence, and feeling visibly ill. Although patients understood their hair loss, the lack of personal control they experienced, as well as treatment control over hair loss was highlighted. In addition, we explored associations between demographic and clinical characteristics, coping and quality of life. In accordance with the Common Sense Model, we did not find associations between demographic and clinical characteristics, coping and quality of life. As explained in this model, making sense of illness, rather than objective illness characteristics, determines patients' responses, and outcomes [11, 38]. Illness perceptions of higher perceived consequences, more concern and more emotional responses were correlated with patients' psychological quality of life. This is consistent with the empirical work in the area of illness perceptions and quality of life in persons with a (chronic) somatic condition [39].

In addition, we demonstrated that illness perceptions of patients with CIA were mostly similar to those of reference samples. Patients in this study attributed fewer symptoms to their hair loss compared to patients with alopecia areata [34], breast cancer [35], psoriatic arthritis [36], and patients in a previous study of our group in patients with CIA [24]. In addition, patients expected a shorter duration of their hair

loss compared to patients with alopecia areata and psoriatic arthritis, which seems reasonable given the chronic nature of these last two conditions. Compared to patients with breast cancer and psoriatic arthritis, patients with CIA perceived themselves to be less able to manage their hair loss. This is an important aspect in the locus of control concept and is acknowledged for its ability to influence patients' coping [40].

In this study, more than half of the patients used scalp cooling and/or head covering to cope with hair loss. The majority of patients described the (highly) positive influence of head covering, which is in line with the literature as it helps patients individualize their appearance and regain partial control [1]. Ten patients reported being informed about scalp cooling and therefore were eligible for scalp cooling, but decided not to use it. This is an interesting finding considering the fact that scalp cooling is the only proven effective method to reduce/prevent hair loss, although its efficacy varies. Literature describes the individual importance of hair and the expected efficacy and expected tolerability of scalp cooling as important factors in the decision to refrain from scalp cooling, which might (partially) explain this discrepancy [41]. However, additional research is necessary about patients' underlying considerations and the information provision by healthcare providers in order to make sure all patients are adequately informed about scalp cooling, and have the opportunity to make their own, well-informed decision.

In this study, patients scored lowest on psychological quality of life, emphasizing the experienced psychological impact of CIA. Influencing the illness perceptions of perceived consequences, concern, and emotional responses seems important in the development of interventions, as this might lead to overall improvement of quality of life for patients with CIA. For social quality of life, a discrepancy was shown, as most patients were less worried about the loss of hair in relation to close relatives and family, compared to interaction with strangers. These findings are in line with previous studies where women did not express concerns regarding the impact of their alopecia with close family members [19], whereas considerable impact of CIA in other social relationships and public involvement is described, leading to minimizing social activities out of fear that others will treat affected patients differently [1, 19, 30]. In addition, family is often ascribed as the most enduring source of support in the personal encounter with cancer [1, 30, 42], possibly explaining the interaction between psychological and social quality of life of patients in this study.

Given patient responses in this study on the functional quality of life, patients seemed less affected in their functional quality of life, as they appear to continue their daily activities. However, this experience varied as some patients described preferring to not go outside, shedding

light on the highly personal experience of hair loss. This finding might be (partially) mediated by the coping strategies used by patients, as the use of a head covering might lead to feelings of regained control over one's personal appearance and hiding the visual illness for the outside world.

Clinical implications

Research regarding the psychosocial impact of CIA is growing, as well as the need for adequate support and education about self-management of patients since very limited interventions have been incorporated in regular clinical care [30]. This study highlighted the perceived lack of control by patients with CIA, which is important for adopting and maintaining adequate coping behaviors and is recognized as an important aspect for health outcomes [40]. Therefore, additional research is indicated regarding interventions to encourage the use of adaptive and constructive illness perceptions; specifically, the lack of control for patients with CIA seems necessary. Current biomedical interventions tend to focus on the prevention of alopecia [21, 25, 30]. However, as the loss of hair seems to a large extent uncontrollable and the success of scalp cooling varies among patients [43], it is advisable to prepare all patients with a risk of severe hair loss for possible hair loss. Very few interventions are implemented to help patients adjust and cope with CIA, which is an important factor for quality of life [30]. Therefore, additional efforts of healthcare providers in fostering patients' sense of personal and treatment control are important, while focusing on patients strengths during and after chemotherapy treatment [30, 44].

A promising self-regulatory intervention that is based on the Common Sense Model is the research by Richardson et al. [14] among persons with head and neck cancer. In their study, the assessment of the B-IPQ is used as the basis for this tailored intervention, focusing on patients' current illness perceptions. To encourage informed illness perceptions, the initial focus of the intervention is on the achievement of improved understanding of the disease and its treatment. Secondly, the intervention focusses on the use of coping strategies for adequate management of the disease. Lastly, an evaluation of the effectiveness of coping strategies, as well as possible concerns about the future are expressed.

Furthermore, it would be useful to explore differences in patients' experienced control, perceived consequences, concerns, and emotional responses compared to other patient groups, possibly leading to additional insights and potential psychological strategies in the development of new interventions for people with chemotherapy-induced alopecia.

Limitations

This study has its limitations. Patients that matched the inclusion criteria were selected by an oncology nurse and asked to participate, which might have caused selection bias as this process might be subjective, possibly selecting patients with known concerns about their hair loss. Included were female patients with a chance of severe hair loss. Whereas some patients experienced the actual loss of hair, others reported the fear of losing hair without the specific experience (yet), e.g., due to the use of scalp cooling. Another limitation concerns the cross-sectional design of this study, because of which causality between associations cannot be determined and no insight is provided into the changes in illness perceptions and quality of life over time. Longitudinal research is recommended to attain insight into patients' illness perceptions, coping and quality of life before, during, and after chemotherapy treatment, as this will specify patients' experiences over time. These additional insights, in turn, might contribute to the development of psychosocial interventions and optimizing the support and information provision.

The functional quality of life comprised of one item as only the minority of patients worked in our study. This may not provide a complete overview of the functional quality of life. Notwithstanding these limitations, we feel that our study contributes to further research and clinical care for people with CIA.

Conclusion

In conclusion, this study demonstrates the relevance of illness perceptions in patients with chemotherapy-induced alopecia. Although patients understand their hair loss, all patients should be adequately prepared for loss of hair, as the impact is not related to the degree of hair loss. The limited degree to which patients believe to be in control of their hair loss is striking. This study provides additional evidence for possible interventions addressing maladaptive illness perceptions in a cognitive-behavioral program, by changing illness perceptions and subsequently improving quality of life.

Declarations

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